HÖGSKOLAN
I SKÖVDE

1977

Drama groups
Stigma challenging and well-being of
individuals with HIV/AIDS in Uganda

Dramagrupper
Stigmautmaning och välmående hos
individer som lever med HIV/AIDS i
Uganda.

Abstract

The purpose of this narrative study was to describe the role and potentials of drama groups for enhancing and maintaining well-being for female drama group members living with HIV in Uganda. Six semi-structured interviews were carried out and analyzed through a thematic analysis. The analysis was made within a theoretical framework based upon Sen's notion of the capability approach and social psychological theories of the self. The results showed that the activities carried out by the drama group empowered the women through increasing their access to important capabilities such as inclusion and self-respect. It further indicated that the women needed other forms of support before being able to benefit from these activities. However, some capabilities were still inaccessible to the women due to obstacles as poverty and harmful gender norms.

Keywords: HIV, well-being, the capability approach, Amartaya Sen, stigma, drama group, performing art, Uganda.

Abstract

Syftet med den här narrativa studien var att beskriva dramagruppers roll och potential för att förbättra och upprätthålla välmåendet för kvinnliga dramagruppmedlemmar som lever med HIV i Uganda. Sex semi-strukturerade intervjuer genomfördes och analyserades genom en tematisk analys. Analysen gjordes inom ett teoretisk ramverk baserat på Sen's idé av the capability approach som kombinerades med socialpsykologiska teorier om självet. Resultatet visade att aktiviteterna som utfördes i dramagruppen stärkte kvinnorna genom att öka deras tillgänglighet till viktiga kapabiliteter såsom social inkludering och självrespekt. Vidare tydde resultaten på att kvinnorna var i behov av annat slags stöd innan de kunde gagnas av dessa aktiviteter. Dock var vissa kapabiliteter fortfarande oåtkomliga för kvinnorna, vilket orsakades av begränsningar som fattigdom och skadliga könsnormer.

Nyckelord: HIV, välmående, the capability approach, Amartaya Sen, stigma, dramagrupp, scenkonst, Uganda.

Acknowledgements

Table of contents

1. Introduction

1.1. Presentation

The notion of well-being has been widely explored in different fields of studies such as epidemiology, healthcare, psychology, organizational studies, sociology and philosophy. Commonly, it connotes an optimal condition which is built up by factors as satisfaction, confidence, physical fitness and health. Definitions of well-being are both complex and multi-dimensional. They vary from a focus on subjective issues as life satisfaction to objective matters like income or productivity. Some definitions include equally aspects as values and cultural context (Billson 2005, p. 23ff).

Early discussions on well-being has concerned the physiological part of the human being, but it has been expanded to include physical, mental and social aspects (WHO, 1948). Recently, the concept has been elaborated in relation to gender and distribution of resources (Grabowska & Rigulska 2011, p. 135). A focus on female well-being emphasises the role of restrictions in female capabilities produced by discrimination, prejudices and other barriers. It prevents women from a full and equal participation and is caused by institutionalized sexism. By highlighting differences of conditions it is possible to identity factors that ground inequalities and impact the well-being for underprivileged groups in society (Billson 2005, p. 29).

One such group are women living with HIV. The disadvantage position of women in social, legal and economic domain are increasing both the psychological burden for women living with HIV and the risk of women to contract the virus. Challenges HIV positive women could meet is for example involuntarily transmitting the decease to their child, getting sterilized against their will and living with increased risk for economical instability due to an denial of women's inheritance and property rights (Avert, 2014). In addition, harmful gender norms reduces the women's rights in sexual relationships, which affects their opportunities to protect themselves. Further, an uneven care-taking responsibility reduces educational opportunities. Consequently, girls and young women have lower levels of accurate and comprehensive HIV knowledge than young men. Therefore women are at a greater risk of getting HIV at an early age

(UNAIDS 2013, p. 78, 79). On the top of these burdens the exposure to HIV related stigma and discrimination could result in loss of income, isolation from communities and inability to participate as a productive member of society. Psychological effects of stigma manifest as feelings of guilt, shame and suicidal thoughts. (UNAIDS 2013, p. 84).

Empowering strategies that are addressing discriminatory practices could be made through collective action. The significance of a participation in collective actions that challenge prejudices could be ascribes to its ability to help individuals to overcome stigma. Positive outcomes can be experienced among other in enhanced self-conception, where individual's can reformulate their view of themselves. (Siegel, Lune & Meyer, 1998, p. 6). Another empowering tool is performing art. Benefits arising from the use of performing arts in community settings are visible on both an individual and community level. Positive outcomes from this tool are related to a development of social and life skills, relieving stress, calming down, dealing with criticism and managing one's own emotions (Daykin et al. 2006).

Strategies combining collective action and performing art is for example found in Uganda, where educational activities are carried out through drama, dance and music. The largest organization providing such activities is The Aids Support Organisation (TASO). The organizations has done a significant contribution for the treatment and support of individuals living with HIV with both medical and psychosocial support. Another aspect in their program is to increase public awareness and knowledge about HIV in local communities. This education is made by drama groups which are composed of HIV positive individuals that are open with their status (TASO, 2014).

To further understand the well-being outcomes of an involvement in drama groups a study of the interactive processes is needed, which is why I define my study relevant to the field of social psychology. A social psychological understanding of interaction stresses the importance of the context. Goffman (2005, p. 2, 3) describes interaction as a relation between acts and situations. He implies that it is necessary to first understand the situation before it is possible to give meaning to the individual and his or her acts. These acts are further regulated by social rules and codes, which entails a

more complex understanding of the individual and his or her acts than a merely psychological one. To study the significance of an involvement in drama groups a target audience will be limited to female drama group members living with HIV in Uganda. The study will highlight their subjective experiences of the involvement and its significance for their well-being.

1.2. Objectives

The purpose of this narrative study is to provide a deeper understanding of well-being for female drama group members living with HIV in Uganda, by describing the role and potentials of drama groups for enhancing and maintaining their well-being.

1.2.1. Research questions

How do female drama group members living with HIV/AIDS describe capabilities important for maintaining and improving well-being?
What is the role of the drama group in developing these capabilities?

1.3. Disposition

The following chapter will describe the theoretical framework forming the understanding of well-being in this study. It will present theories and notions related to the concept. Further it will proceed to an overview of the previous research concerning well-being by describing studies on social support, empowerment and capabilities. Next section will argue for the limitations of the study while the following chapter will describe and justify the methods of the study. After an analysis of the result the proceeding section will develop the findings in a discussion related to previous research. The study will be finished by a presentation of conclusion derived from the research, a reflection about its strengths and weaknesses and suggestions of topics for further research.

2. Theoretical framework

In this section I will describe the theories applied in the study to understand the

phenomenon in focus. I will start with a presentation of Amarya Sen's conception of well-being, the capability approach. This conception is used as an evaluative tool and is not regarded as a theory. Therefore it needs to be supplemented with other theories in order to make evaluations. To further understand the social aspects of well-being the framework is hence complemented with Ervin Goffman's notion of stigma and Charles Horton Cooley's concept of looking-glass self.

2.1. The capability approach

An alternative understanding of well-being with regard to gender and distribution of resources is made through *the capability approach*. The approach defines well-being in terms of what a person is able to be or do, in relation to "one's capability to lead a valuable life". Directing the attention towards a persons opportunities enables a broader understanding of well-being, by including aspects which could have remained unnoticed through a focus on mean income or happiness (Billson 2005, p. 30).

The capability approach has been developed by the indian economist and philosopher Amartya Sen. It is an alternative approach to standard economic frameworks for understanding poverty, inequality and human development. It has emerged as a critique against traditional welfare economics which fuse well-being with either wealth or utility (Clark 2006, p. 2, 3). Sen's contribution to both welfare economics and social choice theory awarded him with the Nobel Prize in Economic Science (Encyclopedia Britanica, n.d.).

The ideas of the capability approach stem from the liberal school of thought. The word "liberal" should not be confused with its everyday use in the political context. Instead it is a philosophical tradition which values individual freedom. The core idea of the approach is for people to have the freedom to lead a life that they consider valuable by having opportunities to take action, be engaged in activities after their desires or to be what they want to be (Robeyns 2005, p. 95).

Sen (1993) describes living as a combination of alternative "beings" and "doings", which together are called functionings. Functionings reflect various states of a

5

person and are composed of different things which the individual succeeds to do or be in life. The set of functionings could vary between being more basic, complex or contextually formed. Some basic functionings, as being able to be well nourished, and some more complex ones, like self-respect or being socially integrated, are likely to be important to all people. Even though many functionings are valuable to the majority, individuals could still differ in their evaluation of them. Functionings that are important to an individual is called value-objects. It is associated with positive connotation and gains its significance from the intrinsic value of the person. It should be separated from the utility notion and be seen as something valuable in itself (Sen 1993, p. 30, 31, 33).

Functionings can be divided into two components, achieved and potential. The first one refers to realized beings and doings while the second is constituted by possible ones to attain (Robeyns 2005, p. 95). If being a teacher is a valuable functioning, then working as a teacher would be an achieved functioning while having the opportunity to be employed as a teacher would represent the potential functioning. Potential functionings are by an other word called capabilities. It consists of various opportunities that are available for an individual when leading one's life. The more capabilities a person have access to, the bigger is the freedom or the options (Robeyns 2005, p. 95). For example everybody should have the opportunity to move freely around the world, but if someone chooses never to leave one's birth place, he or she should also have that option.

From these various opportunities the individual can choose a capability set (Sen 1993, p. 30). Within the capability approach there is however some differences in relation to that notion. An influential contribution to this aspect is made by Martha Nussbaum. She has published one fixed list of capabilities that has been expressed to be "a list of normative thing-to-do". According to Nussbaum it could be used to all social justice issues world wide (Robeyns 2003, p. 68). The list covers ten different areas: (1) life; (2) bodily health; (3) bodily integrity; (4) sense, imagination and thought; (5) emotions; (6) practical reason; (7) affiliation; (8) other species; (9) play and (10) control over one's environment (ibid. p. 73). The use of one definite list has been criticized for narrowing down the applicability of the capability approach. Furthermore, by

implementing this definite list without letting the concerned individuals contribute to its creation one contradict the ideological assumptions of the approach – the involvement of the individual (ibid. p. 68, 69).

From the set of capabilities it is possible to indicate an individuals freedom to lead different types of life (Sen 1993, p. 33). That freedom is related to the means that a person accesses. Means could be described as the material and non-material circumstances that influence a persons capability set, but is most commonly associated with goods and services. The link between a mean and a capability is influenced by three groups of conversion factors: (1) personal conversion factors (e.g. metabolism, physical condition, sex, reading skills, intelligence); (2) social conversion factors (e.g. public policies, social norms, discriminating practices, gender roles, societal hierarchies, power relations) and (3) environmental conversion factors (e.g. climate, geographical location). These factors play a role in a persons ability to convert the characteristics of a means to a functioning. (Robeyns 2005, p. 98, 99).

The capability approach is a normative framework and should not be confused with being an explanatory theory. It is used as a tool to evaluate and measure individual well-being and social arrangements, the design of policies, and proposals about social change in society. The approach is widely used by scholars from different fields, but is mostly represented in development studies, welfare economics, social policy and political philosophy. The capability approach can be used for different purposes. In relation to individuals it can be used to evaluate: several aspects of people's well-being as inequality and poverty, the overall well-being of an individual or the average well-being of the members of a group. Concerning social arrangements it can both function as an evaluative tool for social cost-benefit analysis and a framework for designing and evaluating policies in industrialised and developing countries. The overall purpose is however, according to Sen, to focus "on what people are able to do and be, on the quality of their life, and on removing obstacles in their lives so that they have more freedom to live the kind of life that, upon reflection, they have reason to value." (Robeyns 2005, p. 94).

The understanding of well-being within this framework gives much power and

responsibility to the individual concerning the ability to attain it. Personal values and beliefs are important contributing factors related to the experience of it (Sen 1993, p. 30). Since the capability approach is an evaluative tool or framework it cannot be used to explain well-being. When using it in relation to policy and social change matters it will instead conceptualize and evaluate the notion. Therefore the approach needs to be accompanied with theories of explanatory nature (Robeyns 2005, p. 94). In this essay the theories discussed below will function as an explanatory base.

2.3. Stigma

Within a society there exist categories that are seen as natural and ordinary. They could be regarded as pre-existing assumptions, or normative expectations, of a person's behaviour and character. When an individual possesses a trait which is inconsistent with the normative assumptions of the category in a less desirable way the person looses his or her membership in it. Instead the focus is directed towards the deviant trait and the person becomes stigmatized (Goffman 1986, p. 2, 3).

Stigma is defined by Goffman (1986, p. 3) as a discrepancy between an individual's actual and virtual social identity. The author means that stigma is created through symbols that construct a person as possessing certain discrediting characteristics, which further may lead to humiliation and production of "spoiled identity". This information functions as a representation of the person's whole identity.

Stigma can be experienced in three different ways: through bodily abominations, blemishes of individual character or tribal stigma of race, nation and religion. Within these categories a further distinction is made between discredited and a discreditable individuals. The first is associated with a stigma evident to others whereas the second refers to a hidden one (ibid. p. 4). Individuals living with a stigmatized trait which is physically invisible for others are often dealing with feelings of shame towards both the family and strangers (Goffman 1986, p. 53). It divides people into knowing and not knowing about the stigma, which in turn splits life into separate entities where the individual has different access regarding if people are aware about the stigma or not (ibid. p. 98).

Stigma concerns therefore not only discrediting attributes but includes also relations between individuals and groups: *stigmatized*, *normals* and *wise*. Normals are individuals who do not deviate from a particular expectation at issue. Wise could be describes as normals that are courtesy-members of a stigmatized group. Individuals characterized as wise have had particular experience with a stigmatized group, which has given them more insight about their situation. In turn this has made them sympathise with that group (Goffman 1986, p. 3, 28).

Problems originated from the relation with normals concerns their reactions to the stigma. Most often, but not always consciously, discriminatory actions are performed, which reduces the life chances of a stigmatized individual/group (ibid. p. 3, 5). Further an insecurity of the reactions of the normals could affect stigmatized individuals in ways that they experience difficulties in knowing what other individuals actually think about him or her and makes the individual more self-conscious and calculating about his or her impressions (Goffman 1986, p. 14).

2.4. Looking-glass self

The notion of self includes according to Cooley (1998, p. 164) not only the mind or the body. It is expanded to involve aspects as appearance, manners, deeds, character and friends. The author means that the self rises in contrast to other people, which implies a social nature (ibid. p. 155). To understand the interaction between the self and its social context the author explains the role of self-feelings. Self-feelings are defined and developed by experience and becomes integrated in various components and functions of the individual: muscular, visual or other sensations; perceptions, apperceptions and conceptions; and personal ideas. The concept could be explained as attitudes related to objects, manners, deeds and so on, which the individual relates to her- or himself as "I", "Me", "Mine" or "Myself" (ibid. p. 156). It is not possible to liberate oneself from these attitudes (ibid. p. 165), but the dynamic character of the self-feelings makes it possible to change them over time (ibid. p. 157).

Self feelings are a product of social forces in its context. They are affected by general course of history as in the particular development of nations, classes,

professions and other similar factors (ibid. p. 165). These attitudes has their point of reference in the communicative aspects of general life. This means that the thoughts of other persons are important for the experience of a self-feeling. One example is shame. The experience of it is tied to the a sense of an other person that could impose that feeling. That sense could be evoked by the presence of a distinct and particular individual or more vague and general one, which could be reflected in one's sense of social responsibility (Cooley 1998, p. 161, 164). It is a kind of social reference where we see ourselves through the eyes of others. This process could be compared to a looking glass but with the difference that the social looking-glass imposes judgements on the self. These judgements becomes a realistic imagination of how one's self is appearing in the mind of someone else as well as the attitudes that person is ascribing it, which in turn affecting the self-feelings of the individual. The process could according to Cooley (1998) be divide in three steps: "the imagination of our appearance to the other person; the imagination of his judgement of that appearance; and some sort of self feeling, such as pride or mortification" (p. 164). How the individual will be affected by this judgment depends on the character and the weight of the other person, through whose eyes we see ourselves. We could for example be ashamed to seem "evasive in the presence of a straightforward man, cowardly in the presence of a brave man". In the process of imagining we automatically shares the judgement of the other mind. (ibid. p. 164).

3. Previous research

This part will cover some of the findings made in relation to well-being. It will begin with a brief review of social support and life experiences of women living with HIV. Further it will describe research on empowerment and performing arts and stigma management. The section will be finished with research on capabilities in relation to both unprivileged people and women.

3.2. Social support

In studies describing life experiences of women living with HIV/AIDS the significance

of social support to the well-being of women is highlighted. *Perceived Social Support and HIV/AIDS Medication Adherence Among African American Women* by Edwards (2006) describes the situation of 33 African American women through semi-structured interviews. The study examined the relation between social support and medical adherence and identified factors that prevented the women to adhere well on medical treatment. The results showed that stigma and feeling unloved and uncared for functioned as a barrier to medical adherence.

In *Oaxacan Women with HIV/AIDS: Resiliency in the Face of Poverty, Stigma, and Social Isolation* by Holtz, Sowell and Velasquez (2012) 21 in-depth interviews were conducted with Mexican women. The study explored the lived experiences of women living with HIV without any access to social support. The results indicated that these women lived with an increased psychological burden related to a deprivation of means coping with negative emotions related to the decease. Both studies reflect the situation of poor women living with HIV and focus on psychosocial issues of HIV. Despite cultural differences the findings retail some similar psychosocial burdens as social isolation, stigma and the desire for social support (Edwards 2006; Holtz, Sowell and Velasquez 2012).

Previous research on women living with HIV has explored the significance of social support to the well-being of women. However none of the studies have focused on the impact of group support or collective action to women's well-being. Consequently, more information is needed to create a deeper understanding of elements enhancing the psychosocial well-being of women living with HIV/AIDS. Even tough these studies are not conducted in Africa the results could still provide information of the psychosocial context experienced by women.

3.3. Empowerment and stigma management strategies

Studies on empowerment describe the significance of performing arts to the involved individuals. *In the study Of drama, dreams and desire: creative approaches to applied sex education in southern Africa* Casale and Hanass-Hancock (2011) review six approaches to sex education. The authors stress the usefulness of drama as a means to

create a space for young people to negotiate their social identity and challenge dominant gender roles (ibid. p. 358). They also emphasize the role of teachers since they unintentionally could reinforce gender stereotypes (ibid. p. 363).

In *Young Citizens as Health Agents: Use of Drama in Promoting Community Efficacy for HIV/AIDS* Kamo et al (1998) also address the significance of teachers. They studied the role of children in educating adults through dramas regarding risks and stigma of HIV/AIDS. The data was collected through a survey with 1114 adults and indicated that dramas presented by children increased adult's recognition of the importance of children's participation in HIV/AIDS related issues (ibid. p. 203).

Strategies enabling social integration and empowerment were further explored in Ruud's (2008) book *Community Music Therapy*. The book described Stige's project *Upbeat* (1983), which observed six individuals with Downs Syndrome. The study explored the relation of people with a mental handicap not included in local band activity and their ability to have full membership in the local community. Results showed that individuals not sharing symbolic resources inherent in musical life were prevented from having full membership in the mainstream local life. This was changed by integrating both individuals with and without a mental handicap through music therapy. The action opened up the space for persons with a mental handicap by breaking down some of the boundaries which kept them isolated or segregated from mainstream local life (Ruud 2008, p.5).

Empowering strategies related to stigma management was explored in Sigel, Lune and Meyer's (1998) *Stigma management among gay/bisexual men with HIV/AIDS.* The study was composed of unstructured interviews with 139 men and provided an extensive presentation about different strategies to cope with stigma. The findings showed that the individuals used various strategies that could be classified into three categories: reactive, intermediate and proactive. Reactive strategies tried to hide the stigma while intermediate and proactive strategies implied a disclosing of the individual's status with a variation on the degree of disclosing. The strategies used varied with respect to the time the individual had been living with HIV. Individuals usually started with reactive strategies and proceeded to intermediate and proactive

strategies after some time. People using reactive strategies reported higher levels of psychological distress. The two latter strategies were instead associated with a development of a positive sense of self and the ability to live a meaningful life.

Previous research on empowerment and stigma management has explored the value of various forms of coping. Studies on empowerment has discussed the significance of performing arts to the individuals involved in it, while research on stigma management has focused on the effects of the individual's relation to his or her decease. For this study these results are valuable for a further understanding of the relations between well-being and the engagement in performing arts as well as the relationship with one's decease.

3.4. Capabilities

Research on capabilities important to underprivileged people living in developing countries is made in *The Voices of the Poor – Crying out for change* by Narayan et al. (2000). This collection of studies is based on over 20000 interviews with poor men and women on each continent. One theme explored the notion of well-being in relation to gender. The study showed that men's and women's construction of well-being is often connected with their gender identities. One factor that affected these roles was poverty. Male unemployment was one factor that induced the women to look for anther source of income. This increased livelihood responsibility was put on the top of the women's traditional household responsibilities. In many cases this only added a new aspect on the woman's role instead of changing the stereotypical gender roles. As a result women experienced being overworked and having little time for outside activities such as participating in evening classes, community events or informal socializing.

In *Redefining well-being through Actions: Women's Activism and the Polish State* by Grabowska & Rigulska (2011) female capabilities were studied in relation to abortion issues in Poland. The data consisted of two qualitative studies of women's activism in Poland and a literature and press coverage of the Polish abortion debate and was analyzed trough a discourse analysis. The result showed that women were being denied their reproductive choice due to discriminating practices supported by a foetus

13

focused discourse. It portrayed women as mothers – not as individuals – and prioritized pregnancy over female well-being. By that, women's well-being became "a collective responsibility of the whole society" (Grabowska & Rigulska 2011, p. 146). To challenge the ruling view feminist discourses entered the discussion. By highlighting women's subjectivities and well-being in political discourses the purpose was to reframe women's well-being as an individual matter. The study concluded that female well-being differed due to variations in accessibility to certain resources concerning pregnancies, which was affected by class, age and physical and mental abilities, and was regulated and controlled by the state and its institutions.

Previous research on capabilities has explored various obstacles that prevented the women from accessing capabilities important for their well-being. These findings are valuable for this study for a further understanding of the relations between various factors in the society and female well-being.

4. Limitations

Studies in the previous research section has focused on issues similar to this study. The difference between this essay and the studies presented in the previous chapter could be defined by their approach. Inspired by their perspectives it would have been possible to explore well-being from for example issues creating psychosocial distress and capabilities related to reproductive health or poverty. Since this study is concerned with well-being enhancing factors, rather than managing ill-health a focus on psychosocial issues would not be fruitful. Furthermore, concentrating on capabilities only related to reproductive health or poverty would narrow the women's possibility to define their own well-being and would contrast with the purpose of this essay.

5. Method

In this chapter, I will describe and justify the choice of method for my study. First, I will argue for the general framework and choice of specific method. It will be followed by a description of the sampling, ethical considerations, interview guide and ended with discussions about procedure, transcription, validity and reliability and method of

analysis.

5.1. Choice of Method

This study is conducted within a non-positivistic qualitative tradition. A qualitative research is concerned with human factors and searches for knowledge about individuals' understanding of themselves as their thinking, learning, knowing and acting in relation to cultural, everyday and other situated experiences (Brinkmann & Kvale 2009, p. 12). Further, this essay affiliate with ideas originating from pragmatism. This philosophical tradition is associated with three core assumptions about the reality and its existence. The first rejects the existence of a true reality existing "out there". Instead it claims that the reality is actively created through a dynamic interaction between individual-individual and individual-world. The second idea presumes that individuals create their understanding and experience of the world based on knowledge that is proved useful to them. The third means that this knowledge is derived from the nature of the relation between the individual and the social and physical "objects" in the world, which in turn is defined according to the individuals' use of the "objects" (Ritzer 2008, p. 347).

A narrative methodology is used to explore the individual and his or her experiences of different situations. It is therefore a suitable approach through which it is possible to study identities of individuals. The use of narratives support temporal changes and enables an exploration of past, present and future aspects during the same study. Narratives are divided into several types of stories – bibliographical, autoethnographical, life historical and oral historical – which differ to the extent they examine the life of an individual. A narrative methodological design could be combined with different forms of data collection as observations, documents and pictures, but is commonly used with interviews (Creswell 2013, p. 71, 73). Since this study is concerned with previous experiences it is more suitable to conduct interviews.

For individual interviewing there are two different methods: unstructured and semi-structured. The structure of the first method is closely associated with a normal conversation. The interviewee is allowed to speak and associate freely about a theme which is introduced by the researcher (Bryman 2011, p. 415). The second type has a

15

clearer focus and explores different themes through some prepared questions. Despite this organisation a semi-structured interview is flexible through the possibility to adapt its structure to the situation by for example changing the sequence and forms of the questions in relation to the answers given by the subject (Brinkmann & Kvale 2009, p. 124).

The choice of conducting semi-structured interviews is influenced by the purpose of the study. To be able to describe the common experiences of the participants and compare their answers it is necessary to let the subjects reflect upon the same themes (Bryman 2011, p. 416). A disadvantage of using individual interviews pointed out by Bryman (2011, p. 449) is that contradicting answers or answers that are obviously false seldom become challenged or questioned. Since this study is concerned with individual life experiences and affiliate with ideas from pragmatism it does not claim to describe an objective reality. One risk on the other hand concerns the respondent's willingness to share information. If they choose only to discuss the themes on the surface the derived conclusions may not be valid. To minimize such risk it is important to build up trust in the interviewer-interviewee relationship.

5.2. Empirical Instrument

The interview guide started with background questions and continued to main questions. The main questions were divided into four different themes inspired by the theories and previous research. Each theme started with open-ended questions as "Can you tell me about yourself and your life how it was before getting HIV?". They were either followed by probing questions as "Tell me more about important persons in you life" or directs questions as "What is your favourite activity in the drama group: drama, dance or singing?". The purpose of keeping a flexibility in the interviews and exploring important aspects in the respondent's experiences was enabled by following up questions. On the other hand they could not be included in the interview guide since they arose in relation to the stories of the respondents. The interview guide is presented in its whole in *9. Appendix 1*.

5.3. Sampling

The narrative methodology is characterized by a small sample size which could be motivated by its deep involvement in each participant. When studying life history narratives a more deep and complex understanding of the situation is required and limits the sample to 1-3 participants (Creswell 2007, p. 72, 74). Another more defined type of narrative is oral history. It covers reflections of a specific part of an individual's life. Its purpose is to understand the meaning that arises from a respondent's reflection of specific events and is concerned with their cause and effects. This type of narrative requires less involvement in each respondent's life, which can be compensated by a larger sample size. In this study oral history narratives will be explored. The focus on the individual's experience of the cause and effect of events to their own life is compatible with the purpose of the study, which is focusing on it in relation to the well-being of the participants (Creswell 2013, p. 73). Therefore the sample size and was increased to 6 individuals.

A common strategy used in narrative research is political important sampling. This type of purposeful sampling is used when the stories of a particular group are of interest (Creswell 2007, p. 155). Since this study will highlight female well-being in relation to both HIV and being a drama group member the included participants were required to be HIV positive women which were active members of a drama group. Other inclusion criteria were based on the number of years the women have lived with HIV and been a drama group member. This limitation was made in order to be able to evaluate the role of these factors to their well-being. The final criteria was related to language barriers. In order to reach the personal experiences of the women it was important to get a first hand comprehension of their stories. By using an interpreter the conveyed experience would instead be a description of the interpreters understanding of the women's experience, which is not consistent with the purpose of my study. The inclusion criteria was hence formulated accordingly: English speaking, HIV positive women that have been active drama group members for at least 2 years and living with the virus for at least 5 years. The women who participated in the study had an average

age of 41 years old, lived with HIV for 19 years and been a drama group member for 9 years.

5.4. Ethical Considerations

Reflections upon the maintenance of ethics during the whole research process has been influenced by guidelines provided by the Ugandan National Council for Science and Technology (2007) and Seidman (1998).

Before the interview it was important to consider the subject of the study and its potential effects on the involved participants. Since it addressed a set of traumatic and intimate issues the subject could both be hard to talk about and bring up negative emotions or memories. To minimize the risk of making the respondents uncomfortable the interview guide was revised by an external research committee in Uganda. Another issue taken into account was the economic situation of the respondents. Each participant received a monetary compensation for transport costs and lunch. This was made to not impose any burden on their already difficult economic situation. It could be argued that the monetary contribution was a motivator for the women to participate in the interview, or that it created an unequal relationship where the information was bought from the respondents. To minimize the experiences of "buying" information, it was stressed that their participation was voluntary and that they decided which information they wanted to share.

During the interview a new concern arose – informed consent. To describe the meaning of the respondent's involvement in the study and to relieve them from eventual feeling of unease associated with the interview situation they were involved in the structural process of the study. Therefore the following aspects were presented in the interview situation: the overall research plan, the aim of the research, the research methods, the risks and benefits that the research could entail, who the principal investigator was, the fact that participation was voluntary and that they had the right to cease participation at any time. It was also stressed that the study participants chose what information they wanted to share.

After the interview the concern shifted from only focusing on the study

participants to equally include their stories. A reflection on confidentiality was necessary. To provide anonymity for the study participants the handling of personal information as name and location was de-identified during the transcription. Instead feigned names were used. Their anonymity was further protected by limiting the involvement of other persons listening to the interviews to only include the researcher. To ensure the previous criteria the interviews were deleted after the completion of the transcriptions. The transcriptions, stored on the researcher's computer, did not contain any personal information that directly could be associated with the respondents. Having someone reading their personal stories could nevertheless be perceived as a violation against the integrity of the study participants. To reduce the possibilities of unintended persons to access the transcriptions both the computer and the folder which contained their personal stories were secured with separate passwords.

After completing the research process it was necessary to consider further consequences associated with the respondent's involvement in the study. Seidman (1998 p. 92) highlights that involvement in research could create feelings of alienation, by separating the participants from their words without any further involvement with the results of the study. To reduce the risk of alienation the respondents was e-mailed a copy of the final version of the study.

5.5. Procedure

To get in touch with study participants a collaboration with TASO was established, which enabled the access to a drama group. The introduction to the drama group was made with assistance of a TASO employee during a rehearsal. To include everybody in the meeting the information was translated to the local language. The drama members were informed about the essential purpose of the study, it's inclusion criteria and a monetary contribution covering expenses for transport and lunch. After the introduction the members had an opportunity to ask questions concerning the implications for participating in the study. The interested group members which found themselves fitting the inclusion criteria were further instructed to contact me personally the same day.

The interviews lasted between 50 and 80 minutes and were conducted in an

office at the TASO centre where the initial contact had been made. The interview situation was opened by asking the respondent's of their informed consent. This was made both orally and in written by a presentation of the study and its ethical considerations (see *9.2 Appendix 2.*). An emphasis on the research process and the handling of information was made orally when asking permission for recording. The situation continued with a brief presentation of the interviewer. Before starting with the interviews the study participants were given a possibility to ask any questions about the study or the interviewer. This was made to reduce an eventual experience of a hierarchic relation between the interviewer and the respondent, in order to establish a trustworthy relationship with the respondents before asking them questions in the personal domain. The interview started with background questions and proceeded to the main questions. The order of the questions varied depending on the interaction between the respondent and the interviewer. The closing of the interview situation was created through a possibility for the respondents to express thoughts and feelings related to the situation along with the monetary contribution.

5.5.1. Pilot Study

The purpose of a pilot study is to test the function of the empirical instrument (Bryman 2008, p. 247). In this study an interview was made with one respondent that fit the inclusion criteria. The transcription showed a need of adjustment concerning the structure of the themes in the interview guide. It required as well as more questions related to one of the themes. Despite the different structure of the interview and the lack of information on some questions, the results from this pilot study has been included with the rest since it contributed with information valuable for the study.

5.6. Transcription

The transcription process was divided into two procedures. The first aimed to transform the whole interview into a written text. The second part focused on the content by correcting misunderstandings or misspellings from the previous procedure. According to Bryman (2008, p. 451) transcriptions can be made both with regard to the content and

the language in the interviews. The striving of reflecting a natural conversation is dependent on the significance of non verbal communication, which in turn is a reflection of the analytical approach. In this study the focus has been on the content. Therefore non verbal communication as laughter, humming and accentuations has been excluded in the transcriptions since it rather reflects the interpersonal communication between the respondent and the interviewer and removes the focus from the content.

5.7. Validity and Reliability

Instead of turning to notions as validity and reliability, which are associated with quantitative research, Guba and Lincoln has formulated an alternative criteria adapted to the quantitative field. To evaluate the quality of a study they discuss its trustworthiness and authenticity. These notions differ from the validity and reliability criteria in relation to definitions of truth. While the last mentioned concepts agree with the idea of an absolute truth and thus the existence of one social reality, the trustworthiness and authenticity criteria supports the idea of social reality as consisting of multiple accounts (Bryman 2008, p. 377). The ideological standpoint of the alternative criteria correspond with the one in this study, which motivates its use for evaluating the quality of the research process.

To evaluate trustworthiness this study could be argued to fulfil the credibility and transferability criteria. By letting the an external research committee examine the purpose, method and ethics of the study it could be claimed to reach the credibility demand of good practice. The transferability criteria could be justified by the provision of detailed description of the study participant's context, which supports a discussion about the study's comparison to other milieus.

To evaluate authenticity it could be claimed that the study reaches the fairness, ontological and educative demand. The study reflects the fairness criteria by including women from different backgrounds and age categories in the study, which has enabled a representation of different viewpoints. The nature of the study represents the ontological demand. This was achieved through analyzing components present in the study participant's surrounding and their significance for the well-being of the respondents,

the research could provide the participating women with a better understanding of their social milieu. The educative criteria was reached by sharing the study to TASO, the organization that was responsible for the drama group. Through that the knowledge which arose from the study could reach other actors in the social milieu of the women.

5.8. Data analysis

One of several focuses in narrative analysis is concerned with how people relate past, present and future events to each other. This could be explored through a thematic analysis which focus on the content of the stories rather then how they are told (Bryman 2008, p. 553). A thematic analysis could thus be a useful tool for approaching the study participant's experiences.

The analytical process started by examining the interviews separately through coding procedures proposed by Strauss and Corbin in Bryman (2008, p. 543). This was made to elaborate themes for the thematic analysis. The coding procedure resulted in categories for each interview which were presented in separate diagrams. The processes was finished by a comparison of the interviews, which developed joint themes and sub themes. It resulted in three major themes with related sub themes. The identified major themes were: previous obstacles, functionings and desired capabilities.

A challenge when reconstructing the respondent's stories is the influence of the researcher's own personal and political background (Creswell 2013, p. 76). My pre understanding of this phenomena has been formed by the theories and the previous research presented above. During the analytical process I tried my best to as well be aware of cultural differences in regard to norms and practices and the political context.

6. Result and Analysis

The findings were divided into three main themes: 1) Previous obstacles included self-stigmatization; and discrimination and exclusion; 2) Functions involved physical condition and appearance; self-respect and disclosing; and inclusion; 3) Desired capabilities embodied care for family members and occupational satisfaction. Within

each theme the results were analyzed and interpreted in relation to the theories from the theoretical framework.

6.1. Previous obstacles

The main theme of previous obstacles included sub themes as self-stigmatization and discrimination and exclusion. It described feelings and experiences of the women before getting in touch with any kind of support and obstacles that had an negative impact on their well-being.

Self-stigmatization. When receiving the result of the diagnosis or when suspecting HIV the respondents described having gone through feelings of shock, fear, loss of hope of living or being in self-denial. They associated HIV with death and thought there was no other option but to die: " *I went back home I cried. I cried. I'd not say anything at home. I could not eat, I could not drink anything. I said "Let me die." - Harriet.* Losing hope of living made half of the study participants refuse to accept support. Instead they expressed a wish to die. One respondent described this stage as a *psychological torture*. Four of the women were either pregnant, had just given birth or were breastfeeding. On the top of the worries related to their own life they also feared for the life of their child: *"(...) I went for an HIV test. And by that time I was breastfeeding, I didn't know my status but I was breastfeeding my kid. I was so confused." - Ritah.*

Further the study participants started seeing themselves as different from others: *"useless, weak* or *vulnerable"* and that they would live a *"miserable life".* Visible symptoms of HIV made them feel shame over and uncomfortable with their body:

> *"I was very very small and I used to be a thin thin woman. You see me now, I'm fat*
> *but I was thin and thin and thin. And everyday I was going thinner and thinner and*
> *thinner. I was almost dead." - Marble.*

Some of the study participants also experienced feelings of loneliness, that they were the only person living with HIV: *"I had not seen a young person HIV positive. I said "It*

seems I'm the first person" so my feelings were so bad." - Harriet. This experience made them wanting to keep their status a secret because of worries of the reactions of others. One such worry was rejection and not being able to have an intimate relationship, as in not finding a husband or having children. Another one was being blamed for their status. One respondent was preoccupied to not be loved and accepted by her fellow church members: *"I thought "What would people say when I disclose that I'm HIV positive? And yet I'm a born again." That thing kept me in denial." - Laura.*

When getting diagnosed with the decease the women's self-feelings changed towards negative ones. This reaction could be compared to Cooley's (1998, p. 164) theory of the looking glass self which describes the evaluative process of one's self. The normative judgements of HiV positive individuals functioned as a point of reference for the women to establish their own worth and evoked a self-stigmatizing behaviour. It created a fear of being discriminated by others which forced them to hide their status. This reaction could be compared to Goffman's (1986, p. 113) theory of stigmatized individual's relation to their own stigma. The negative association with the decease created a wish for the women to distance themselves from it. According to Goffman (1986, p. 88) this is a common reactions for individuals living with a hidden stigma. It divided the study participant's social world into people knowing and not knowing about their status, which imposed a psychological burden to them.

Discrimination and exclusion. Five women had experienced negative reactions from neighbours, friends and/or family members when disclosing their status. The most common reaction by neighbours and friends was to to exclude them from the social community, by stigmatizing or de-humanising them by for example grabbing some of their properties. One respondent was denied help by the local leaders of getting her piece of land back since she *"was going to die"* as her HIV positive husband. Being stigmatized did also affect the relation to family members. One respondent was rejected in cases where the family members was worried of being associated with the stigma:

"My children feel bad when I go public. Like the daughter stopped me from going

24

to her school "mummy, you should tell the other people but never come to my
school and stand and start telling the school that you are HIV positive. I don't like
that." And I had to respect her view so I don't go there." - Janet.

Three of the study participants were widows and alone with the care taking responsibility of their children. The exclusion was experienced as a psychological burden for them since it created a worry for their children as well:

"It was very hard for me because I was not working and we were staying in a city.
We needed to eat but I was not working. The children had to go to school but there
was no money. They could fall sick but nothing I could do. Nothing. Life became
very very very hard." - Winfred.

Being excluded and/or rejected created feelings of distress within the women, especially when it was made from people they trusted in. The citation above shows that family members as well are affected by normative judgements of HIV positive individuals. To avoid discrimination and/or to protect the family members from that it became necessary for the women to hide the stigma and to live, as Goffman (1986, p. 84) calls it, a double life.

Bodily changes and stigmatizing attitudes imposed by others and themselves created obstacles in the study participant's life. This indicated that conversion factors preventing the women from living a valuable life existed in the personal and social area.

6. 2. Functionings

The main theme of functionings included sub themes as physical condition and appearance; self-respect and disclosing; and inclusion. Bodily functions and appearance was related to a good physical condition, as in being physically fit and free from illness and the significance of being good looking. An important means was ascribed to medical support. Self-respect and disclosing and inclusion described interpersonal relations that opened up the social environment of the respondents. Important means

were associated with counselling, support from family members, the interaction with drama group members and the new role as an educator and performing arts.

Physical condition and appearance. The first step of de-stigmatization was experienced in relation to their body. Both their physical condition and appearance was expressed as important in creating the feeling of being "normal". Experiencing themselves as healthy, being able to use their body as they wanted and getting female capabilities back rose the women's hope to live. The capability of being able to use their body as they wanted was expressed as symbol of getting their life back:

> *"(...) a person living with HIV is a normal person like another person. You can sing you can dance you can jump you can do each and everything. You can give birth, yeah. It's just the matter of how you are living." - Ritah.*

Not showing any physical symptoms of sickness and being good looking was equally an important aspect. The respondents described themselves as "good looking, healthy or normal". It made them feel proud of themselves and was significant for their self-esteem. Putting these two capabilities together – physical health and appearance – the women were able to disassociate themselves from stigmatizing beliefs and become something more:

> *"When I don't tell someone that I'm HIV positive somebody cannot understand it by sight, except when I'm the one introduced myself to him or to her. You can't know that I'm a positive woman." – Marble.*

Through these bodily changes the women did not fit into the stereotype of an HIV positive individual, which gave them the chance of being associated with another category. According to Cooley (1998, p. 164) the self is constructed of diverse aspects, as the body, appearance and character. The self-feelings are therefore derived from various aspects of a person. This change was according to the women enabled by the

26

medication:

> *"After 4 months, I remember very well I started gaining, gaining power gaining power little by little. I started helping myself, I started washing clothes for myself, simple simple clothes. And after one year I was able to come alone here at TASO to get drugs" – Laura.*

From the citation above the medical treatment was described as a significant means and brought the respondents to a condition which made them capable of engage themselves in social life and being independent.

Self respect and disclosing. Accepting one's status and disclosing it was described as important for the women. Not feeling shame of being HIV positive was associated with freedom of expressing themselves and their needs:

> *"If someone comes and says "You are HIV positive" it will never hurt you because you know what you are. And then secondly, if you are HIV positive you do not fear to take your drugs anywhere. Even if you're in a taxi and it's time for your drugs obviously you take your drugs." - Harriet.*

From the citation above it could be argued that the respondent had changed her relation to the decease. Further more the women expressed being liberated from worries related to judgements of other people. According to Cooley (1998, p. 164) this is made by changing the point of reference through with an individual evaluate her- or himself. By this it is possible to change the normative judgement of one's own person which in turn change the self-feelings. An important mean in the de-stigmatization process was counselling. The initial counselling provided the study participants with both emotional and informational support and taught the respondents a new way of living:

> *"After learning that I was HIV positive I got scared thinking that maybe I'll die the*

next year (...) but I went through counselling and I came to know that it wasn't the end of my life. So the counsellor supported me, she gave me guidelines which would help me to live with the virus (..) so I tried to follow whatever she told me and here I am." - Janet.

Through the support from the counsellor the women's relation to their own stigma changed. According to Cooley (1998, p. 164) the self is as well reflected in the deeds of a person, which makes habits important for a person's experience of oneself. The new way of living enabled thus the respondents to create a new more positive understanding of themselves. The counselling also provided them with a possibility to build a relation to someone who could show sympathy, or as Goffman (1986, p. 28) would call it, someone wise. Instead of reflecting themselves in the eyes of the normals, and thus associate themselves with the dominant view of HIV positive people, the respondents could define themselves through the eyes of a wise.

Inclusion. Being socially integrated in various groups made the women access different capabilities described as important: being accepted, being cared for and to be able to care. Integration in the family provided the women with both emotional and instrumental support as in being loved and getting help with medication. Compared to the challenges some women experienced when being excluded from the family (see *6.1 Previous obstacles*) these respondents were in a less vulnerable position. Respondents not receiving any support from parents or sibling reported getting valuable care from children:

"I've been telling them slowly by slowly. Now they are big, they understand everything and they are supporting me, like taking my medication when they are back for holidays. They always counsel me, we sit and talk "mummy you should not do this, mummy you should not get annoyed, mummy you should take your drugs promptly because we need to see you, we still need you, eyh"" - Janet.

28

Both including family members and being accepted by them transferred the family members from being normals to become wise. It provided the respondent's with a space where they could be themselves without having to hide their stigma (Goffman 1986, p. 36). Another important group mentioned by the respondents was the drama group. Belonging to a community enabled emotional support and contributed to bring forward positive self-feelings by challenging stigmatizing ideas. A collective coping with difficulties associated with the decease created a space where it was possible for them to renegotiate the normative judgement defining themselves. By that the drama group members created a social setting where the women accepted them as they were, for example with the new habit of taking medicines:

"But then when we are there in our drama group joking that, when we say when it is time to swallowing tubs, we say: "Oh my dears, we take tubs at this time our daily mean." We call it daily mean. We call it daily mean because everyday we have to swallow tubs. Everyday. Every time you have to take your tubs." - Marble.

This citation also expresses a mutual understanding of their situation, which according to Goffman (1986, p. 117) could be used to create an appropriate attitude towards oneself. The inclusion further provided the respondents with opportunities to both laugh, play and enjoy life. Sharing similar experiences was another way for the respondents to both receive and provide emotional and informational support. Most of the respondents described it as important to cope with issues related to their daily life:

"There are so many things we talk about we women because some they are also like me. They didn't have husbands and they had children and they say "Oh Ritah, you will manage. You will manage. You will just be strong. You will manage." They comfort you, they tell you how to survive. (...) So that's where I got that strength to look after my children." - Ritah.

Another outcome of being a drama group member was to enter a new role as a teacher.

29

The different functions of the teaching role enabled the women to include HIV to their identity in a positive way. All of the study participants experienced being proud of themselves. When talking about the significance of being a drama group member the study participants described themselves as an "example for the community". One way to include HIV to their identity was for example made by using the respondents' personal experiences when educating the community about HIV, which made them feel important and useful:

> *"There are communities that never have seen positive people healthy. They have that aspect, they think that whoever is HIV positive must be thin, have rashes, have everything. So when they look at us we are an example. We are a good example to the community and it inspires other members to come out. If we say "Please I'm Harriet, I tested in 2004. Please, I'm doing this. Look at me I'm doing well". They say "Ok, I can also get tested." - Harriet.*

Through this teaching role the participants could interact with normals without being stigmatized. In that way they widened their social sphere. In other words they were included and accepted in the community. The interaction between stigmatized and normals is according to Goffman (1986, p. 120, 121) affected by ideas of how the stigmatized person should behave towards other groups. One communication strategy tries to reach a common point of reference and direct its attention to the human dimensions of the communication. An important mean to reach that point of reference was through the use of performing arts:

> *"When you don't go with the drums and when you don't sing loud when you don't shout they don't come. They'll say: "Who are those. Who are this group there?" They are some people they don't know what we have to come to do. But when you sing and dance, people just, even if they have been digging there in this road they, the ones, they go there and come to see this people: "What are they doing?" After singing then you stop after dancing you stop. When the people have come so many then you start telling them about AIDS. And after telling them about AIDS people*

can understand. They are agree" - Marble.

This new interaction with people in the community was a way for the women to challenge normative judgement of HIV positive individuals. It also provided the women with another "mirror" that reflected positive attitudes towards them:

"By the time we finish there everyone is asking "Don't you leave you people, I have some more questions. I have some more questions. Wait for me please." Eyh, and by the time you came people would not even bother to look at you. But after doing that "When will you come back please? How do we contact you people? I wanted to you to take you to a certain school. You go to schools also to help young ones?" Yeah, that's what we do and it helps a lot. Cause in the villages people never loved me, just as I told you, people never liked me not even look at me" - Winfred.

Another study participant reported drama as a way to become something more, as a means to highlight other qualities of the person:

" You know everything needs changes (...) to show some people that I can do this, I can also did this. If I can be a kid I can also be a counsellor. I can also be a mother. I can also be a friend." - Ritah.

The use of performing arts was not only used as a mean to communicate with the audience. It was also described as a mean for providing emotional support. The respondents experienced an emotional ease when being engaged in their favourite activity. It was an instrument for them through which is was possible to both deal with negative emotions as well as bringing forward positive ones as joy, happiness and playfulness. Three of the respondents compared it to therapy or medicine:

"I like it because I keep smiling. I keep my face happy all the time. I forget all the problems I have in this world. I forget about the decease, that it's there. I don't

even think about it. That, you know, music and dance is a therapy. Since it is a

therapy to us, or to me mostly, it has done a lot in me" - Winfred.

From the citations above it could be argued that the engagement in performing art functioned as a space where the women could feel free to express themselves. Related to Cooley's (1998, p. 164) evaluative process through the looking glass self this engagement could function as a space which released the study participants from the normative judgements of HIV positive individuals and allow them to enter new roles. By changing the point of reference the women could relate to themselves in another way which gave rise to other self-feelings.

The various forms of support and activities addressed different conversion factors that enabled the women to transfer the means to desired functionings. The medical support was significant for personal conversion factors through its improving of the physical condition and appearance. The social support provided by counsellors and the family members coped with issues related to personal conversion factors, by addressing the self-feelings on an individual level. The social support provided by the drama group members and the new role dealt with social conversion factors by targeting social norms and the role of being HIV positive on a group and community level. Performing art had two functions, it addressed conversion factors in both the personal and social domain through its focus on emotions of both the respondents and the audience.

6.3. Desired capabilities

The main theme of desired capabilities involved sub themes as care for family members and occupational satisfaction. The obstacles preventing the women from accessing these capabilities were ascribed to poverty, harmful gender norms and discriminating practices.

Care for family members. Apart from issues directly caused by the problem of HIV the women experienced that livelihood responsibilities had an impact to their social well-

being. The study participants wished to be able to provide material support for their family members, both children and parents. It could be through resources and services as food, clothes, health care and education. Being alone with the livelihood responsibilities was experienced as a psychological burden and caused a lot of distress:

> *"You see my children they don't even have a father in law no. All of them are dead of AIDS. They have only me. I'm the mother I'm father I'm the uncle I'm the everything for my kids. When I think of that for myself "When I die maybe tomorrow if I die where will I leave my children?" I leave them on the streets without having anywhere to stay because their fathers died when they were still young. I wish I could get money. But what I could do first is to buy a plot. At least, if I could put there a small house (...) Because my children in fact they are on the streets." - Marble.*

Having an own house was associated with a dimension of security and described as a means to reduce the worries related to sustentation:

> *"Most of our members are renting. They are staying in rental houses. Some of them are staying with orphans, they don't have husbands. They are taking care of their children. So buying food, paying for the house rent, paying school fees for their children is hard." - Janet.*

> *"My dream is to finish my house. When the house is finished I'll see everything going on well. Cause the money we have been using to pay the rent will be at least taking us to another step and at least be able to save and get my business that I've been wanting" - Harriet.*

Owning a house was experienced to create an opportunity to develop their present situation as well as their future. Having sustentation issues did also have social consequences. To avoid them some women forced themselves to work more, which reduced their time for resting or engage themselves in other activities:

"When you are poor people start despise you. They take you as nobody because you cannot help yourself, you cannot depend on yourself. So, I'm working to that to fit into that. I'd become a responsible woman who is able to do everything I need in my life and to help my son to reach his expectations (..) That's why i'm working day and night." - Laura.

The burden of not having enough resources to support the family did not only impact the women's material life but did as well affect their role as a care taker of the family. Being able to support the family without imposing a burden on others was therefore another important dimension in the care taking responsibility.

Being a drama group member was by the women seen as a means for their economical survival. This kind of social organization was expressed by the respondents to enable two opportunities – to widen their social network and to improve their talents in performing arts – which in turn could be used by the women to get an income:

"I sing on occasions, parties, anywhere I can sing. I know one day one time I'll make it also to be a great singer, musician. (...) Because when you are here in the drama group so many people see you. When you are doing something they advice you, they always tell you "No try this or try this or try this." So I think when I'm still here one day one time I'm going to make it." - Ritah.

However this form of occupation was not seen as a long-term solution for the study participants, who instead wanted a job with a regular income.

"You know in Uganda poverty is a problem to us. You can work hard and work and work and you earn very little. So it's my prayer to have something that can make me, what can I cay, which I can do and rely on it, which can give me enough money. And I admire people other people in their big big shops. I'm capable but because I don't have capital. That's the only thing I'm lacking." - Laura.

34

Occupational satisfaction. All the study participants stressed the importance of occupational satisfaction, ranging from studying at the university to diverse forms of payed labours that were intrinsically valued by the respondent. Some of the women explained that this would increase their feelings of *"being someone important"*. Others expressed that the knowledge gained from formations would make them more involved in social life. Having an adequate level of education could expand the women's possibilities to engage themselves in other spheres of the working life and enable them to use their potential. One respondent expressed the that the knowledge gained from family planning was significant to her personal life. By challenging harmful gender norms the study participant could increase her opportunities to control her own life and body:

> *"I have rights, like having children frequently. If I was still down in those, that life [in the village], maybe I would not even know that "Nahah, producing many children and I don't have a good income, it's bad." I'd continue, but now I can say that "Ah, three kids are enough. I can't continue having more."" - Janet.*

Factors preventing the women from developing these capabilities could be connected with inadequate social protection, discriminating practices and social norms. The most common reason for being unemployed was due to an unequal care-giving responsibility in marriage:

> *"I was working first, but he stopped me from work when I had my first born. He said I stay home and look after my children. We were ok because he had money and he was looking after us very well. But when he started falling sick things became harder. Because he was done looking after the family and, you know, we had to survive that. Life started becoming hard." - Marble.*

For other respondents insufficient education was the primary factor. Not having the opportunity to finish school could be ascribed to social conversion factors as inadequate

social protection and social norms. All of the respondents were dependent on their family's economic situation for having the possibility to attend school and most of the study participant's families did not have enough money. For girls or women devoted from both education and work, marriage was seen the sole option. Instead of being dependent of the family's support they had to rely on the husband:

"I was just 15. That's when I gave my firstborn birth. And in that marriage I gave him 3 kids. But when the third kid was just making one month it has an accident and he died. So, this was the second man who convinced me to fall in love with him, and he also begged me to stay with him, which for me I thought it was very ok because I had no husband and I needed someone to help me, because I had already three children I had no one to look after them so I agreed." - Ritah.

Another factor that the women perceived interfering could be related to discriminating practices or power abuse. Most organizations only employ their own relatives, which reduced their possibility to enter the labour market:

"Like you can see here in Uganda. If someone is a manager and there's a vacancy for a day centre supervisor he or she must do what is necessary for the family member or the friends to come and join this position. So if you're not known it's not easy, unless you've started up your own business." - Harriet.

Obstacles preventing the women from accessing desired capabilities could be related to both personal and social conversion factors. Social conversion factors involved public policy, harmful gender norms and discriminating practices. They limited the women in their social life by excluding them from economical or material support to sustain the family and denying them access to various spheres as work and school. These consequences were also reflected in the loss of capabilities on an individual level which were experienced as lack of free time and knowledge and/or skills.

7. Discussion

This section will start by deepening the interpretations risen in the previous chapter. These interpretations will be related to findings made from previous research in order to evaluate the significance of the means and obstacles in relation to the well-being of the study participants. Following, there will be a presentation of the conclusions drawn from the study and a discussion about their relevance in a wider societal context. There will also be a critical reflection about the findings by discussing circumstances that might have affected the results and strengths and weaknesses of the study. Lastly, a suggestion of further research will be made.

7.1. Significance of the means and obstacles

Effects of the medical treatment increased the physical capacities of the women. It enabled them to take part in social life by being physically capable to engage themselves in activities of the everyday life. However the respondents experienced limitations in their social environment, especially in relation to medical adherence. Before joining the drama group the respondents avoided to take medicines in public. In combination with social support and acceptance of one's status the women's worries related to taking medicines in public were reduced. By that they gained the courage to perform that act, which could be interpreted as a uniting between different parts of self and the world. Through this they could improve both bodily and psychological aspects of their well-being. Similar findings were found in Edwards (2006) where HIV positive women experienced being limited in their medical adherence by stigma and embarrassment. By disclosing their status to their family members it reduced their worries associated with taking medicines at home. These findings indicate that medical support needs to be combined with social support to increase medical adherence and the overall well-being of the women.

The effects of social support were reflected in the respondent's acceptance of themselves and their increased the access to various social environments. The support received from the counsellor reduced the women's level of mental distress. By both

dealing with negative emotions related to the diagnosis and suggesting new ways of living the study participants got empowered to continue living. The significance of support dealing with emotions related to the HIV infection was as well highlighted in Holtz, Sowell and Velasques (2012). In their study HIV positive women were deprived from such support and reported a high level of mental distress from unresolved anger and fear. This result suggest that support from a counsellor addresses the issue on an individual level. It is important for the emotional development on an intrapersonal level, but did not support the respondents with identity issues on a group level.

The social support provided by family members made the respondents feel important and valuable which functioned as a motivation to continue living. Respondents deprived from family support lost access to an important means to increase their social well-being. The importance of family support is also stressed in Holtz, Sowell and Velasques (2012), where it was framed as a means of getting out of social isolation. This outcome indicate that a good relationship with family members is important for the creation of a positive sense of self. The interpersonal relation with family members contributed to develop a positive social identity within the family, however it did not give the respondents further access to other social environments.

The peer support obtained by the drama group member's empowered the respondents by creating an accepting environment and increasing their conscious about issues related to HIV. Through the stigma challenging climate the women got the possibility to develop alternative ideologies concerning HIV which gave them courage to disclose their status in a larger scale. These findings are comparable with the effects discovered by Siegel, Lune and Meyer (1998), where HIV positive men experienced a reinforcement of a positive collective identity through interactions with other infected people or individuals holding a favourable attitude towards HIV positive people. These findings indicate that peer support is important in the de-stigmatization process by helping the respondents to accept their status and to create a positive collective identity. The group relationship contributed to both expand their social environment and to create an authentic identity.

The role as an educator empowered the women by creating a positive collective

identity among people in the community. It enlarged their social sphere to reach the community level. The use of the educator role as a means for getting access to other social domains is also found in Kamo et al's (1998) study, where adults recognized the importance of children's participation in HIV/AIDS related issued after being educated by children. This result suggest that the educator role could be used to increase and spread positive attitudes towards minority groups in the community, which in turn contributes to enlarge their involvement in community life.

The role of performing art was significant in the interaction process, for the respondent's social identity and for the emotional development for the respondent. Through this means the respondents got the required attention to be able to communicate with and get recognized by other people in the community. It was a way for them to express and get affirmed of various qualities. The other function of this means was to process negative emotions and bring forward positive emotions. The quality of performing arts as a means to inclusion has been confirmed by Stiege (1986). In his study the use of music broke down some of the boundaries that kept people with a mental handicap isolated or segregated from the mainstream local life. Regeneration of the social identity through performing art is also mentioned in Casale & Hanass-Hancock (2011). The involvement in drama created a space where it was possible for adolescents to challenge dominant gender roles and negotiate their social identity. The significant impact of performing arts on emotions has as well been found in Daykin et al. (2006). The study showed that an involvement in music, performance, drama and dance was related to psychological benefits as stress relieving and managing emotional distress. These outcomes indicate that performing art could be used to bridge the gap between a minority group and the community by creating a space where both groups could meet and communicate. It also suggest that it could have transformative impact on both individual's social identity and emotions.

Obstacles preventing the women from accessing desired capabilities were found in the economical, political and cultural domain. Poverty and harmful gender norms were factors that increased the psychological burden for the women by creating a heavier work load or restricting their opportunities of participating in desired activities,

as studying or starting up an own business.

Harmful gender norms reinforced the role of a woman as a care taker or a mother which put the study participants in a position where they were expected to behave according to the norms. This division of labour created an economical subordinance which limited their opportunities to make their own choices through the dependency it created. Within the role of a traditional woman the study participants did not have much power to affect the situation. Similar experiences were found in both Nayaran et al's (2000) and Grabowska & Rigulska (2011) research, where women experienced being restricted in their life choices by both the stereotypical gender role duties and the increased livelihood responsibilities.

A redefinition of both female and male roles could increase the access to capabilities for both. Since well-being often is connected to gender identities it is necessary to increase the access to "female" and "male" capabilities for each role. A one sided change risk to worsen the situation. This was shown in Narayan et al's (2000) study where the female role was added more responsibilities when the man couldn't be in charge of the economical sustainment. Instead of changing responsibilities the expectations of the male role deprived the men from engaging in the care-taking responsibility while the women lost their free time, which resulted in a limitation of capabilities for both roles.

One way to challenge stereotypical gender roles was discussed in Grabowska & Rigulska's (2011) article. They stressed the need of highlighting women's subjectivities and well-being in the political discourse. Since the present construction of female well-being has become a "collective responsibility for the whole society" (Grabowska & Rigulska 2011, p. 146) where the women were denied their reproductive choice, the authors also pointed out a need to reframe the women's well-being to an individual matter.

In accordance with the results in Nayaran et al's (2000) and Grabowska & Rigulska's (2011) this study further indicated that the accessibility to certain resources also was affecting the women's well-being. The women lost access to the desired resources due to a denial of educational choice and/or working choice. To increase the

access it is therefore necessary to revise public policies and to involve responsible actors for this situation, the state and its institutions.

7.2. Conclusion

The study described the significance of different roles to the female drama group member's well-being and different factors and actors that could affect their opportunities to improve their well-being. As presented above the issue of HIV involved various aspects of the study participant's life. It affected their relation to themselves, family, friends and community members. To reduce its consequences different forms of support and activities were experienced as beneficial.

The results indicated that the majority of the obstacles could be related to stigma, poverty and harmful gender norms. To overcome obstacles related to stigma the women benefited from various forms of support or activities at different stages. The significance of the activities carried out in the drama group was important to their role in a group or a community setting. It increased their possibility to get included in different communities by reducing the impact of stigma. To be able to engage themselves in the drama group various forms of support, as medical support, counselling and family support, was necessary.

A conclusion derived from these findings is that the drama group has an important role in the improving and maintaining of the well-being of the women, but they can't benefit from them without first receiving support from other sources. Siegel, Lune and Meyer (1998) arrived at similar conclusions in their study. Their findings showed that the first type of stigma coping was made on an individual level before the study participants could benefit from coping on a group and community level, by for example engage themselves in public education or social activism.

The results in this study further indicated that in the domains of education, work and care-giving responsibility the issue of gender identity and poverty did limit the women's opportunities to engage themselves in desired activities. To overcome these obstacles policy changes addressing poverty and harmful gender norms issues need to be made. A conclusion made from these results is that support programs targeting

women therefore need to involve aspects addressing these obstacles.

7.3. Strengths and weaknesses

In this study both strengths and weaknesses could be identified. One of the strengths could be associated with the focus of the study. The study has problematized the understanding of well-being by exploring it from an underrepresented angle – the aspect of gender. This was enabled by the use of the capability approach, which highlights the individual's own definition instead of analyzing it from predefined categories. The benefit of this openness could also be ascribed to the possibility of making cross-cultural research, since it takes the context into account without imposing the researcher's cultural standards as a frame of reference. These qualities makes it suitable for being used in research within the social psychological domain. A social psychological approach to the issue of HIV is beneficial for a further understanding of the consequences of HIV not only to the affected individual but as well to the HIV positive's surrounding. This makes the finding not only interesting to policy makers or health program developers but could also be beneficial to family members, friends and community members.

Some issues in the study could be interpreted as a weakness, for example the study's ability to meet the purpose. Instead of only focusing on the role and potentials of drama groups it has as well discussed the significance of various means of support. It could therefore be claimed that a too large focus was directed towards surrounding factors. However this was made to discuss the role of the drama group and the well-being of the women in a larger context. Another factor which could have enhanced the quality of the study would have been a focus on cultural aspects. This would have enabled a deeper understanding of the significance of the functionings described by the women. A bigger focus on that in the interview guide would have been necessary to accomplish it.

7.4. Further research

Throughout out the study different aspects of performing art was discussed – its significance for the relation between the audience and the women as well as the women's relation to themselves. However, no attention was directed towards the significance of performing art to the relationship between the drama group members. To further understand the role and potential of drama groups to the well-being more research is needed to explore the role of performing arts to the interaction between the drama group members and the significance of performing art as a means of communication to them.

In this research the significance of other people have been studied to explore their impact on the well-being of the women. Another aspect that could be important to study is the impact of culture. To provide a deeper understanding of the capabilities and functionings important for women the aspect of culture needs to be more prominent. Therefore a similar research could be made with that aspect in focus.

8. References

Avert. (2014). *Women and HIV/AIDS.* Available: http://www.avert.org/women-and-hiv-aids.htm. (Retrieved: 02 March 2014)

Billson, J.M. (2005). "The complexities of defining female well-being." In J.M. Billson & C. Fluehr-Lobban (ed.), *Female well-being*, (pp. 23-44). London and New York: Zed Books.

Brinkmann, S., & Kvale, S. (2009). *InterViews: Learning the Craft of Qualitative Research Interviewing.* USA: SAGE publications.

Bryman, A. (2008). *Social Research Methods*. New York: Oxford University Press.

Bryman, A. (2011). *Samhällsvetenskapliga metoder.* Malmö: Liber.

Casale, M., & Hanass-Hancock, J. (2011). "Of drama, dreams and desire: creative approaches to applied sex education in southern Africa. " *Sex Education,* 11, 353-368.

Clarc, D.A. (2006). "Capability Approach." In D.A. Clark (ed.), *The Elgar Companion to Development Studies*, (pp. 1-18). Cheltenham: Edward Elgar.

Cooley, C.H. (1998). *On Self and Social Organization*. Hans-Joachim Schubert (ed). Chicago: The University of Chicago Press.

Creswell, J.W. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (3rd edition). USA: SAGE publications.

Creswell, J.W. (2007) *Qualitative inquiry and research design: Choosing among five approaches* (2nd edition), USA: SAGE publications.

Daykin et al. (2006). *The effects of participation in performing arts for young people: a systematic review of the published literature 1994-2004,* Bristol: University of the West of England. Available: http://hsc.uwe.ac.uk/net/research/Data/Sites/1/GalleryImages/Research/Young%20People%20and%20Arts%20Report.pdf. (Retrieved: 17 April 2014)

Edwards, L. V. (2006). "Perceived Social Support and HIV/AIDS Medication Adherence Among African American Women." *Qualitative Health Research*, 16, 679-691.

Encyclopaedia Britannica (2014). *Amartya Sen*. Available:
http://www.britannica.com.login.libraryproxy.his.se/EBchecked/topic/534266/
Amartya-Sen (Retrieved: 05 September 2014)

Goffman, E. (2005). *Interaction ritual: Essays in face-to-face behaviour.* Transaction
Publishers: New Jersey.

Goffman, E. (1986). *Stigma: Notes on the management of spoiled identity.* USA: Simon
& Schuster

Grabowska, M. & Rigulska, J. (2011). "Redefining well-being through Actions:
Women's Activism and the Polish State." In A.E Woodward, J-M, Bonvin & M.
Renom (ed.), *Transforming gender well-being in Europe: the impact of social
movements*. Cornwall: Ashgate.

Holtz, C.S, Sowell, R. & Velasquez, G. (2012). "Oaxacan Women with HIV/AIDS:
Resiliency in the Face of Poverty, Stigma, and Social Isolation." *Women &
Health*, 52, 517-535.

Kamo, N., Carlson M., Brennan, R. T., & Earls, F. (1998). "Young Citizens as Health
Agents: Use of Drama in Promoting Community Efficacy for HIV/AIDS."
American Journal of Public Health, 98, 201-204.

Kvale, S. (1996). *InterViews: An Introduction to Qualitative Research Interviewing*,
USA: SAGE publications.

Narayan, D. et al. (2000). *Voices of the Poor: Crying Out for Change.* New York:
Oxford University Press.

Ritzer, G. (2008). *Sociological Theory*. New York: McGraw-Hill.

Robeyns, I. (2005). "The Capability Approach: a theoretical survey". *Journal of Human
Development*, 6, 93-111.

Ruud, E. (2008). *Community Music Therapy.* Available:
http://www.hf.uio.no/imv/personer/vit/evenru/even.artikler/CMTherapy.pdf.
(Retrieved: 15 Februry 2014)

Sen, A. K. (1993). "Capability and well-being" In M. C. Nussbaum & A.K. Sen (ed.),
The Quality of Life (pp. 30-53). Oxford: Clarendon Press.

Seidman, I. (1998). *Interviewing as Qualitative Research: A Guide for Researches in
Education and Social Sciences.* New York: Teachers College Press.

Siegel, K., Lune, H., & Meyer, I. (1998). "Stigma management among gay/bisexual men with HIV/AIDS." *Qulitative Sociology,* 21, 3-23.

Stieg, B. (2007). "The Grieg Effect – On the Contextualized Effects of Music in Music Therapy". *Voices – A World Forum For Music Therapy*, 7. Available: https://normt.uib.no/index.php/voices/article/viewArticle/548/409. (Retrieved: 17 April 2014)

TASO. (2014). *TASO Mulago.* Available: http://www.tasouganda.org/index.phpoption=com_content&view=article&id=77&Itemid=225. (Retrieved: 02 March 2014)

Ugandan National Council for Science and Technology. (2007). *National Guidelines for Research Involving Humans as Research Participants*. Available: http://www.uncst.go.ug/dmdocuments/Guideline,%20Human%20Subjects%20Guidelines%20Marc.pdf (Retrieved: 16 February 2014)

UNAIDS. (2013). *Global Report – UNAIDS report on the global AIDS epidemic 2013.* Available: http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2013/gr2013/UNAIDS_Global_Report_2013_en.pdf. (Retrieved: 05 February 2014)

WHO. (1948). *WHO definition of Health.* Available: http://www.who.int/about/definition/en/print.html. (Retrieved: 10 March 2014)

9. Appendix

9.1. Appendix 1. Interview guide

1. Back ground information:

Age
Family status
Education
How long have been living with HIV
How long respondent participate in drama group

Main questions

1. Hiv:

Can you tell me about yourself and your life how it was before getting HIV?
How it was after getting HIV?
How was it after joining the drama group?
How would you describe its effects on your life (if at all) on:

> life opportunities: what you can do or be in life
> life plans
> daily routines
> relationship with others
> identity
> self-esteem
> internalized stigma
> feelings/emotions

Tell me about important persons in your life.

2. Drama groups

Tell me more about your self and why you joined this group.
What this group is about?
How often do you meet with the drama group for training and performances?
What kind of performances do you have?
What is your favourite activity in the drama group: drama, dance or singing ?
Typical and/or unusual performance.
Some situation, episode/situation during a performance, if you may recall some, describe in
details (what happened, some feelings, thoughts, observations about yourself and others, how would you explain this)
Can you recall if there were some performances that has touched you emotionally more than others. If so, tell me more about that.
Tell me about the different roles you have during the drama.

What do you feel when playing these different roles?
Tell me about the reactions of the audience during/after a performance.
How do the reactions of the audience make you feel?
How do you interact with the audience after a performance?
What is more important to you, the rehearsals or the performances?
Are you using your drama, dancing and singing skills in other domains outside the drama group? Describe the relation you have with the other members in the drama group.
How do these relations make you feel?

3. Capabilities

What is important in life for you, to do and to be?
What is "good" life for you?
Can you say that your life is good enough?
If no, what do you need to have good life?
What plans do you have for the future?
Do you have anything that could prevent you from attaining them?
Describe your hopes.
Describe your dreams.

4. Social meaning of being a drama group member

How would you describe the effects of the drama group (if at all) to the community?
What does being a member in the drama group mean to you?
How do you think your life would be if you weren't a member of the DG?
Do you think that you would look at yourself differently if you didn't live with HIV?
Do you think that the drama group has had any impact to your feelings towards HIV?
Would you recommend other individuals living with HIV to join a drama group?

9.2. Appendix 2. Informed Consent Document

RESEARCH INFORMED CONSENT FOR THE PROJECT

"Drama groups: Stigma challenging and well-being of individuals with HIV/AIDS in Uganda"

Introduction: Hello my name is Josefina Andersson. I am a bachelor student at the University of Skövde, Sweden. I am here in Uganda to conduct interviews for my degree project. This project is financially supported by the Swedish International Development Cooperation Agency, SIDA, a government agency which mission is to reduce poverty in the world. The aim of my project is to learn more about psychosocial well-being and of members in TASO's drama groups.

Invitation to Participate: I would like to invite you to participate in my study, but your participation is completely voluntary. You can refuse to answer any of the questions in the interview, stop it at any time, or you can tell my when a question makes you uncomfortable and we will skip that question. I will ask you some questions about you, your experiences of the participation in the drama group and reflection about HIV. I expect that the interview will take around 45 to 60 minutes.

Risks an Benefits: I do not expect there to be any risk to you associated with you participation in this study. For the participation you will receive a compensation for travel expenses and lunch. Although this study may not benefit you personally, I hope that these results will help us learn more about the psychosocial well-being of women living with HIV/AIDS in Uganda.

Confidentiality: Your participation in this study will be confidential and the answers you provide will be stored securely in my computer which is locked with two different kinds of passwords. Your name and any other identifying information will be accessible only to me and will never appear in any sort of report that might be published or shared with organizations who are interested in the results.

Questions & Concerns: Please ask me anything you want to know about this project now or later. You can contact me on the phone number or e-mail below with any problems or questions you may have.

> Phone number: +46 73 XXX XX XX
> E-mail: josefina.andersson@xxxxx.com

If you have questions about your rights as a study member, you can also speak with Dr. Etukoit, the Chairperson from the TASO Institutional Review Committee at XXXX XXX XXX.

Consent: If you agree to participate in the study, please check the box and sign or write

your initials to show that you understand the information above and that your consent is given voluntarily.

☐   ☐
YES   NO

Respondent's name:_____Date:_____

Signature or initials of respondent:_____

Signature of person obtaining consent:_____